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EXAMINING LEGISLATION TO IMPROVE PUBLIC HEALTH

THURSDAY, SEPTEMBER 8, 2016

House of Representatives,

Subcommittee on Health,

Committee on Energy and Commerce,

Washington, D.C.

The subcommittee met, pursuant to call, at 10:00 a.m., in Room 2322, Rayburn House Office Building, Hon. Joseph R. Pitts [chairman of the subcommittee] presiding.

Present: Representatives Pitts, Guthrie, Barton, Burgess, Blackburn, Lance, Bilirakis, Long, Ellmers, Bucshon, Brooks, Collins, Green, Engel, Schakowsky, Butterfield, Schrader, Kennedy, Cardenas, and Pallone (ex officio).

Also Present: Representative Roybal-Allard.

Staff Present: Paul Edattel, Chief Counsel, Health; Adrianna Simonelli, Professional Staff Member, Health; Heidi Stirrup, Health Policy Coordinator; Waverly Gordon, Minority Professional Staff

Member; Tiffany Guarascio, Minority Deputy Staff Director and Chief Health Advisor; and Samantha Satchell, Minority Policy Analyst.

Mr. Pitts. The subcommittee will come to order. The chair will recognize himself for an opening statement. Today's hearing will examine several different legislative proposals that will address various aspects of the Public Health Service Act.

H.R. 1192, the National Diabetes Clinical Care Commission Act, amends the Public Health Service Act to foster more effective implementation and coordination of clinical care for people with prediabetes and the chronic diseases and conditions that result from diabetes.

Today, our witnesses will also be discussing potential changes to legislation that will make it less disease-specific, so the focus can be broader, to include related autoimmune and metabolic syndromes. According to the Centers for Disease Control and Prevention, CDC, almost 29 million Americans have diabetes, and an estimated 86 million American adults have prediabetes. Diabetes is the seventh leading cause of death in the United States. It is the leading cause of kidney failure. The total national cost associated with diabetes in 2012, according to the CDC, exceeded $245 billion. One in three Medicare dollars is currently spent upon people with diabetes. There are 35 Federal departments, agencies, and offices involved with implementation of Federal diabetes activities. And this legislation will establish a commission to evaluate, recommend solutions for better coordination of patient care and ways to control costs across all of these offices.

And I thank my colleague, Representative Pete Olson, for

sponsoring this important legislation, which will be welcome news for over the over 100 million people afflicted with diabetes or prediabetes.

H.R. 1717, the Sober Truth on Preventing Underage Drinking Reauthorization Act, or the STOP Act, sponsored by Representative Roybal-Allard of California, provides for programs and activities to prevent underage drinking.

H.R. 1807, the Sickle Cell Disease Research, Surveillance, Prevention and Treatment Act of 2015, sponsored by Representative Danny Davis of Illinois and Dr. Michael Burgess of Texas, would reauthorize the Sickle Cell Disease Demonstration Program. Sickle cell disease has no cure. It leads to premature death. This legislation will hopefully move us one step closer to improving the quality of care and symptom management for those afflicted.

H.R. 3119, the Palliative Care and Hospice Education Training Act, sponsored by Representative Engel of New York, increases the number of permanent faculty in palliative care at accredited allopathic and osteopathic medical schools, nursing schools, social work schools, to promote education and research in palliative care and hospice and to support the development of faculty careers in academic palliative medicine.

H.R. 3952, the Congenital Heart Futures Reauthorization Act of 2015, sponsored by Representative Bilirakis of Florida, coordinates Federal congenital heart disease research efforts and improves public education and awareness of congenital heart disease.

Today, we will hear from one panel of experts and stakeholders as to their ideas and recommendations on these various bills.

We welcome all of you, and I now yield to Dr. Burgess.

[The prepared statement of Mr. Pitts follows:]

******** COMMITTEE INSERT ********

Mr. Burgess. Thank you, Mr. Chairman.

And it is with a great deal of pleasure that I recognize from my neck of the woods, Dr. Leffert being here today. He is the president-elect of the American Association of Clinical Endocrinologists, and in another life, I used to refer patients to Dr. Leffert from my practice in Louisville, Texas, down to the big city specialist.

So, Jonathan, it is great to see you again. It is great to have you here as part of this committee.

And Ms. Banks, who is here on behalf of the Sickle Cell Disease Foundation, who will be talking about the disease that Danny Davis and I, Representative Davis and I, introduced a bill. We are going to be looking at legislation that seeks to identify and improve the overall public health of our country, and one of those bills is 1807, the Sickle Cell Disease Research, Surveillance, Prevention and Treatment Act of 2015. You know, it was back in the middle 1970s when I was a resident at Parkland Hospital, our obstetric service there, Dr. Jack Pritchard, Dr. Eric Cunningham, sickle cell disease in pregnancy was a special project that they put a lot of effort into. And as a consequence, we ended up seeing a lot of patients referred from around the country to the program there at Parkland Hospital in the middle 1970s. It had been some time since I thought about it again, and then, with Representative Davis at one of your meetings here on the Hill, it really struck how there really hadn't been the advancements in this area that I thought there would have been by this time. So that is one of the

things that this committee has been very active in the Cures for the 21st Century. We want those things that are supposed to be there by now, and I would include this as one of those things that we want to be there by now.

So thank you, Mr. Chairman. I will back and await the discussion.

[The prepared statement of Mr. Burgess follows:]

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Mr. Pitts. The chair thanks the gentlemen and now yields to the ranking member of the subcommittee, Mr. Green of Texas, 5 minutes for an opening statement.

Mr. Green. Thank you, Mr. Chairman.

I want to welcome our panel today, and thank you for taking your time to come before us. We are examining five pieces of legislation that will improve public health and build on this committee's record of advancing and enacting very bipartisan bills. I want to thank the chairman for calling the hearing and our witnesses for being here with us this morning.

H.R. 1192, the National Diabetes Clinical Care Commission Act, was introduced and championed by my colleague on our committee but also my neighbor in Houston, Pete Olson, Congressman Olson, and Dave Loebsack, who is also a member of our committee. We would be considering a manager's amendment on H.R. 1192, which would establish a national clinical care commission to evaluate and offer recommendations to improve care, leverage resources, and coordinate efforts around complex metabolic, autoimmune, and insulin-related diseases. Through innovation and collaboration and maximizing return on investment, this important legislation provides the opportunity to address the enormous economic and human impact caused by diabetes and other disorders, and I am proud to be a cosponsor of this legislation.

H.R. 1717, the Sober Truth on Preventing Underage Drinking and Reauthorization Act, or the STOP Act, was introduced by Representative Lucille Roybal-Allard. She has been a tireless champion for this

issue. In fact, she has talked to me -- I think we came to Congress in 1993 -- and she has talked to me all of the time since then about trying to deal with drunk driving. I want to recognize her, as she is here, and thank her for her leadership.

The STOP Act will build on successful efforts to reduce underage drinking by reauthorizing a number of important public health programs and add an additional component of screening and intervention.

H.R. 1807, the Sickle Cell Disease Research, Surveillance, Prevention and Treatment Act, will enhance our ability to understand and survey and treat sickle cell disease. Sickle cell disease is a group of inherited red blood disorders that affect approximately 100,000 Americans. Unfortunately, it is difficult to diagnose, as symptoms can be severe, and the treatment requires comprehensive and complex care.

H.R. 1807, introduced by Representative Danny Davis and Mike Burgess, also on our committee, will promote research and prevention and treatment and emphasizes collaboration of community-based entities focusing on sickle cell disease.

H.R. 3119, Palliative Care and Hospice Education and Training Act, is an important bill to improve palliative care. Representative Eliot Engel, also a member of our committee, introduced this legislation, recognizing that palliative care enhances the quality of life for individuals with serious and life-threatening disease by treating the symptoms, the side effects, and emotional pain experienced by patients. H.R. 3119 would improve training for health

professionals, enhance research in palliative and hospice care, and support projects to fund the training of physicians and nonphysician healthcare professionals entering the field of palliative care.

Finally, we are considering H.R. 3952, the Congenital Heart Futures Reauthorization Act. Each year, approximately 4,000 babies are born with congenital heart defects, making it the most common type of birth defect in the United States. It is estimated that 1 million children and 1.4 million adults live with congenital heart disorders. They require specialized care and face a lifelong risk of disability and premature death. The cause is unknown, but several genetic and environmental factors have been linked in the diseases. H.R. 3952, introduced by Representative Gus Bilirakis, also from our committee, and Adam Schiff and Eleanor Holmes Norton, builds on existing efforts by requiring the Centers for Disease Control and Prevention to enhance and expand its research, surveillance, and education outreach to providers and the public about congenital heart diseases. Under this legislation, the CDC would report to Congress on a cohort study to improve the knowledge of epidemiology of the disease across lifespans and implement an awareness campaign. I am proud to support each of these important bills and thank our sponsors and our committee for their commitment to improving public health and look forward to hearing from our witnesses and learning more about each of these bipartisan pieces of legislation.

Mr. Chairman, unless someone else wants my last 30 or 40 seconds, I will yield back.

[The prepared statement of Mr. Green follows:]

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Mr. Pitts. The chair thanks the gentleman.

I now recognize the vice chair of the full committee, the gentlelady from Tennessee, Ms. Marcia Blackburn, for 5 minutes for opening statement.

Mrs. Blackburn. Thank you, Mr. Chairman.

I want to thank our witnesses for being here.

And I am so pleased that we are taking some time to go through these bills. They all have a significance to public health. The diabetes bill, I had the opportunity before coming to Congress to serve on the Diabetes Association Board in my State, and I appreciate Representative Olson's good work on looking at this issue.

Of course, the underage drinking bill, when I was in the State senate, this is something at the State level where we put a tremendous amount of effort and energy, and Tennessee, my home State, continues to do so. I know that Reps. Davis and Burgess have worked hard on the sickle cell disease. It does need more attention. It needs more research. It needs more focus, so we are pleased to see that.

We all have heard about palliative care, the importance of that, as we have been at home and in our districts and talked to families and to healthcare providers and beginning to think this through and look for new models. And certainly, in Nashville, we have a tremendous amount of research and new focus that has come to bear on the delivery of palliative care. So I am pleased that we are moving forward there. You know, I have to say that H.R. 3952, going back to my days as being on the Board of Friends of Children's Hospital in Nashville and dealing

with congenital heart disease, and as a mom and a grandmom now, having friends and knowing of families, individuals from church, that have a baby that is born with CHD, and just seeing firsthand, living through the anguish and the desperate reach for resources that can help with this, that can extend the life of that child. I am so pleased that we are moving this forward. I do hope that we will see NIH and other research entities focus on how we deal with this so that these precious children will live long past that 18th birthday and will be able to move toward enjoying a full and productive life.

Mr. Chairman, I will yield my time to whomever would like it.

[The prepared statement of Mrs. Blackburn follows:]

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Mr. Pitts. Anyone on the majority seeking time?

If not, the gentlelady yields back.

The chair now recognizes Judge Butterfield, North Carolina, 5 minutes for opening statement in place of Mr. Pallone.

Mr. Butterfield. Thank you. I too want to thank you, Chairman Pitts, for holding this important hearing on reauthorizing important programs to combat the sickle cell disease and on improving diabetes awareness and care. Let me join my colleagues in thanking the five witnesses for coming forward today to testify and to give us the benefit of your expertise. I know you just didn't wake up this morning and come to this room. You have been preparing for this day, and we thank you for your work.

Sickle cell disease and diabetes disproportionately affect African American citizens, including many in my congressional district in North Carolina. In fact, more than 30 years ago, I lost a first cousin to the disease. The two diseases, if not properly managed, can land people in the hospital multiple times. In fact, a 2010 study published in the journal of the American Medical Association shows that people with SCD are hospitalized nearly three times per year. Many people who have SCD are unaware of it before tests can confirm the illness. Even those who know they have SCD find themselves back in the hospital with problems with pain or other morbidities. SCD is a serious disease which can dramatically reduce life expectancy. A study in the New England Journal of Medicine found that the median age for men with SCD is only 42 years old. For women, it is 48 years. The

disease is caused by a small genetic abnormality that deforms blood cells and causes them to block blood flow. SCD can lead to the development of other conditions, ranging from heart disease and stroke to kidney or liver problems.

It is estimated, Mr. Chairman, that 100,000 Americans have SCD. Many more have sickle cell trait, although they never experience symptoms, may not even know that they have the trait. Children can inherent SCD if both of their parents have SCD or sickle cell trait and certain genes are passed on to them. Many of those who have SCD are African Americans. More than 1 out of every 400 African Americans have SCD. That is 1 out of 400, and 1 of every 13 has the sickle cell trait.

And so I applaud my friend and colleague Congressman Danny Davis and other colleagues that have done likewise -- from Chicago -- for his longtime advocacy for SCD health programs and his reintroduction of H.R. 1807, the Sickle Cell Disease Research, Surveillance, Prevention and Treatment Act of 2015. This legislation is a priority for many members of the Congressional Black Caucus, and I am proud to support it. And this important bill would reauthorize the sickle cell disease Treatment Demonstration Program, improve research and surveillance of the disease, and support a grant program for States to develop and implement prevention and treatment strategies.

This bill, Mr. Chairman, is a clean, a clean, reauthorization and would not increase government spending. It is a meaningful first step to help prevent and treat SCD, and I urge my colleagues to support this

important bill. We can, we must do more to support those with this disease. SCD does not currently have a cure. No treatments have been approved since 1998. For that reason, I have long advocated to include SCD in the Pediatric Priority Review Voucher Program, the PRV, run by the Food and Drug Administration. I am encouraged that there is currently a viable treatment in clinical trials at the FDA, but we must do all we can to spur innovation in rare pediatric disease spaces. More than 100,000 Americans are counting on us to support sickle cell disease prevention and treatment programs and need our help to find a cure. I urge my colleagues to support 1807, and I yield back. Thank you.

[The prepared statement of Mr. Butterfield follows:]

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Mr. Pitts. The chair thanks the gentleman.

That concludes the opening statements. As usual, the written opening statements of all members will be made a part of the record.

And we welcome, as was noted previously, Congresswoman Roybal-Allard to sit with the committee today.

Without objection, so ordered.

And I ask unanimous consent to submit the following for the record: a letter from 43 organizations representing physicians, allied health professionals, patients, community health organizers, and industry; as well as statements from the Academy of Nutrition and Dietetics, Novo Nordisk, and Diabetes Advocacy Alliance, all regarding H.R. 1192; and both a statement from the American Society of Hematology regarding H.R. 1807 along with their State of Sickle Cell Disease 2016 Report.

Without objection, so ordered.

[The information follows:]

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Mr. Pitts. I will now introduce the panelists in the order of which they will speak, and as usual, your written statements will be made a part of the record, and you will each be recognized for 5 minutes for a summary.

So, first, Dr. Jonathan Leffert, acting director and president-elect of the American Association of Clinical Endocrinologists; secondly, General Arthur Dean, chairman and CEO, Community Anti-Drug Coalitions of America; and Sonja L. Banks, president and COO of Sickle Cell Disease Association of America, Inc.; then Dr. Sean Morrison, professor and vice chair, Brookdale Department of Geriatrics and Palliative Medicine, Icahn School of Medicine at Mount Sinai, and director of the National Palliative Care Research Center; and, finally, Dr. Brad Marino, chair, Pediatric Congenital Heart Association.

Thank you for coming today.

And, Dr. Leffert, you are recognized 5 minutes for your summary at this time.

STATEMENTS OF JONATHAN LEFFERT, M.D., FACP, FACE, ECNU, PRESIDENT-ELECT, AMERICAN ASSOCIATION OF CLINICAL ENDOCRINOLOGISTS; ARTHUR DEAN, CHAIRMAN AND CEO, COMMUNITY ANTI-DRUG COALITIONS OF AMERICA; SONJA L. BANKS, PRESIDENT AND COO, SICKLE CELL DISEASE ASSOCIATION OF AMERICA, INC.; R. SEAN MORRISON, M.D., PROFESSOR AND VICE CHAIR, BROOKDALE DEPARTMENT OF GERIATRICS AND PALLIATIVE MEDICINE, ICAHN SCHOOL OF MEDICINE AT MOUNT SINAI, AND DIRECTOR, NATIONAL PALLIATIVE CARE RESEARCH CENTER; AND BRAD MARINO, M.D., MPP, MSCE, CHAIR PEDIATRIC CONGENITAL HEART ASSOCIATION

STATEMENT OF JONATHAN LEFFERT, M.D., FACP, FACE, ECNU

Dr. Leffert. Thank you, Mr. Chairman, and, Dr. Burgess, for your kind words. My name is Jonathan Leffert, and I am a clinical endocrinologist from Dallas, Texas, and the current president-elect of the American Association of Clinical Endocrinologists. On behalf of our 7,000 members, I would like to thank you for this opportunity to testify about H.R. 1192, the National Diabetes Clinical Care Commission Act. The subcommittee should be commended for addressing diabetes and recommending to expand the scope of H.R. 1192 to include other metabolic and autoimmune diseases and diseases resulting from insulin deficiency and insulin resistance. We appreciate the opportunity to work with the bill's sponsors, Representative Pete Olson and Representative Dave Loebsack, in this subcommittee on consensus

language to amend H.R. 1192.

I will focus my comments today on diabetes, which represents a significant part of my medical practice as a clinical endocrinologist and is the most prevalent of the diseases that will be addressed by an amended H.R. 1192.

According to the Centers for Disease Control and Prevention, the number of Americans diagnosed with diabetes over the course of the last 35 years has increased more than fivefold, from 5.5 million Americans in 1980 to 29.1 million in 2014. The CDC estimates that there are 86 million Americans with prediabetes, a condition known to progress to diabetes without appropriate intervention. Diabetes is also the catalyst for many other diseases. Diabetes is the leading cause of new cases of blindness among adults. Diabetes is the leading cause of kidney failure. Diabetes causes increased death rates from cardiovascular disease and higher rates of hospitalization from heart attack and stroke. Diabetes is the seventh leading cause of death in the United States. The total cost of diabetes to the Nation in 2012 exceeded $322 billion. Sixty-two percent of this cost is borne by the U.S. Government through programs like Medicare and Medicaid. By 2025, the total cost of diabetes is projected to reach $514 billion, a level comparable to the entire Medicare budget. Our Nation cannot afford for the current diabetes prevalence and cost trends to continue. Congress should not let another session go by without addressing this critical health crisis.

H.R. 1192 provides a cost-effective approach to begin to address

diabetes and the many other diseases and diagnoses encompassed by this legislation. The commission established in H.R. 1192 will provide a venue where the expertise of specialists, primary care physicians, allied healthcare professionals and patient advocates will help our Federal Government partner to evaluate current programs so they are meeting the goal of improving the quality of patient care.

The commission will also facilitate improved coordination and communication among Federal agencies. Consider the example of the FDA approved continuous glucose monitors, referred to as CGMs. These devices are indispensable to patients with type 1 diabetes by allowing them to constantly monitor blood glucose levels. Patients with this device no longer fear losing consciousness from low blood sugar or enduring complications from constantly high blood sugar levels. Nearly all private insurance plans cover CGMs. However, once a patient turns 65 and enrolls in the Medicare program, coverage for this lifesaving device is no longer available. Remedies to fix these issues often require an act of Congress, which places Congress in a position to do the job of the regulatory agencies that failed to work together.

Having the commission available to work through issues such as this will help all parties to find and implement meaningful solutions. The expertise on the commission would also be utilized to prioritize the clinician training and deployment of new revolutionary technologies, such as the artificial pancreas, to ensure patient access to these medical innovations is not comprised.

Agencies can and must work together in a coordinated national

response driven by research experts, specialists, healthcare professionals, and people living with diabetes. The commission established under H.R. 1192 will help achieve this important objective.

On behalf of the American Association of Clinical Endocrinologists, I would like to thank the members of the committee for the opportunity to testify today on H.R. 1192, and I urge you to act now and move this bill forward, ensuring its passage by the U.S. House of Representatives as soon as possible.

In addition to the 220 Members of Congress who have cosponsored H.R. 1192, including many who are members of this committee, I would like to thank the 45 organizations representing the patients, physicians, allied health professionals, community organizations, and industry, and the Diabetes Advocacy Alliance, who have helped to advance this legislation.

[The prepared statement of Dr. Leffert follows:]

******** INSERT 1-1 ********

Mr. Pitts. The chair thanks the gentleman for his summary and now recognizes General Dean 5 minutes for his summary.

STATEMENT OF ARTHUR DEAN

Mr. Dean. Chairman Pitts, Ranking Member Green, and esteemed members of the Subcommittee on Health, it is my pleasure to testify in support of H.R. 1717, the Sober Truth on Preventing Underage Drinking Act, so-called the STOP Act.

I would also like to thank the bill's sponsor, Congresswoman Lucille Roybal-Allard, for her steadfast leadership on this issue, and I thank you for the support and leadership you provided to us.

I am General Arthur Dean, currently serving as the Chairman and CEO of Community Anti-Drug Coalitions of America, a membership based, not-for-profit organization, commonly called CADCA. CADCA is a national nonprofit organization, and our mission is to build and strengthen the capacity of local citizens, and we put them into what we call community coalitions designed for them to have the capacity and the skills to build safe, healthy, and drug-free communities in the U.S. and around the world. We work with more than 5,000 communities in the U.S., and it is our role to be here. And they are very, very concerned about the prevention and the reduction and combatting underage drinking. Back in 2003, the National Research Council and the Institute of Medicine published a report titled "Reducing Underage Drinking: A Collective Response." This report cited serious

underage drinking and recommended critical components for a national strategy to reduce alcohol consumption by minors. The original STOP Act builds upon these recommendations, and in 2016, the bill passed the House of Congress with a unanimous bipartisan support. Authorization for the law expired in 2010, as you know, which makes it urgent that Congress pass a reauthorization as soon as possible.

H.R. 1717, the STOP Act reauthorization bill, would maintain and enhance the original provisions of the STOP Act, and quickly I would describe some of those things that we are concerned about. It reauthorizes the highly successful community-based coalition enhancement grants. We take trained coalitions and give them a small grant to work this issue. Provides grants for current and former drug-free community grantees and partners and allows them to partner with higher education to prevent underage drinking on college campuses. It reauthorizes the Interagency Coordinating Committee to Prevent Underage Drinking -- we call that ICCPUD -- which coordinates the efforts of 16 Federal agencies to combat this problem. It reauthorizes a highly visible national adult-oriented media campaign to raise the awareness of this issue and provide education. It reauthorizes epidemiology studies on excessive drinking and analyzes how young people drink and how they obtain alcohol in the relationship associated with that.

And, lastly, 1717 creates a new grant program for pediatric healthcare providers. We think it is important that those that are treating our youth understand and focus on best practices around

screening, brief intervention, and referral as appropriate.

In the 10 years that have passed since STOP Act was created, it is clear that law's coordinated provisions have effectively been reducing underage drinking. As we look at the most recent Monitoring the Future study, it shows that lifetime alcohol use by those in the 8th grade, 10th grade, and 12th grade is currently at the lowest level since each of these grades were included in the study. While this is welcome news -- it is important news -- underage drinking continues to be a very serious problem that is faced in this country: 17.2 percent, or nearly one in six, high school seniors still binge drink, which is unfortunate. Between 2006 and 2010, approximately 4,300 young people under the age of 21 died from excessive drinking, which is critical. And the total annual economic costs of underage drinking are estimated at $24.6 billion.

So H.R. 1717 builds upon the effective data-driven, Drug-Free Communities Program as the most cost-effective way to prevent and reduce underage drinking. The community-based coalition enhancement grants included in the STOP Act are just one vital component of a comprehensive approach to improve public health and address underage drinking.

I respectfully urge the committee to support swift passage of H.R. 1717, the Sober Truth on Preventing Underage Drinking Act. I will be submitting a detailed statement for the record, which includes information for your consideration.

And we ask that, as in the past, that this bill be unanimously

supported and passed quickly so that it can become law during this session of Congress. I thank you so very much for your attention to this issue, and we understand that underage drinking, although data says we have made progress, there is much progress that still needs to be made, and many, many young people will be better served if this passes, takes place quickly. Thank you very much.

[The prepared statement of Mr. Dean follows:]

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Mr. Pitts. The chair thanks the gentleman.

I now recognize Ms. Banks 5 minutes for your summary.

STATEMENT OF SONJA L. BANKS

Ms. Banks. Good morning, Chairman Pitts and Ranking Member Green --

Mr. Pitts. Could you turn on the microphone now? The light should be on.

Ms. Banks. Good morning. Chairman Pitts, Ranking Member Green, this distinguished committee, thank you for holding this hearing and allowing me the opportunity to testify in support of H.R. 1807, the Sickle Cell Disease Research, Surveillance, Prevention and Treatment Act. I also would like to thank Dr. Burgess, the lead Republican cosponsor of this legislation, and Representative Butterfield, for their leadership on this important legislation. We would also be remiss if we did not recognize Representative Danny Davis for not only leading this important legislation but remaining one of the sickle cell community's key champions.

I am here representing the Sickle Cell Disease Association of America, the Nation's only organization working full-time on a national level to resolve issues surrounding sickle cell disease and sickle cell trait. Since 1971, SCDA has been on the forefront for improving the quality of life, health, and services for individuals and families impacted by sickle cell disease, promoting policies and research and

fighting for a universal cure.

Now allow me to take you on a journey. I want you to think about the worst pain that you have ever experienced in your life, a broken bone, a stomach virus, a flu, or maybe for you women in here who have children, labor pains. Now I want you to take that pain, and I want you to magnify it by two. Now magnify it by five. Now magnify it by 10. Now imagine the pain hitting you at any time, anywhere, with no control, no treatment, and no way to manage it. Now imagine it rearing its ugly head monthly, weekly, and even daily. Though not the journey we all long for, it is one that is a reality. These unpredictable pain episodes are the hallmark of sickle cell disease and the reality for those who are afflicted with it. They can start as early as 6 months of age and span throughout the lifetime, impacting school, work, and ordinary daily living.

Sickle cell disease is an inherited blood disorder affecting approximately 100,000 Americans. This disease causes the destruction and deformation of red blood cells, producing extreme complications that could include stroke in children and adults, lung problems, chronic damage to organs, including kidneys, liver and spleen, and, yes, severe painful episodes, and even death. One in every 400 African American newborns have sickle cell disease, as does 1 in every 1,200 newborns in Hispanic descent.

Despite its first noted discovery well over 100 years ago, progress has been relatively slow, and the sickle cell community still faces numerous challenges. For instance, the average life expectancy

of a person with sickle cell disease is relative young, age 40 to 45. Presently, there is only one medication that has been FDA approved to treat this disease. There is an overwhelming shortage of physicians that treat or specialize in sickle cell disease, which makes it very difficult for patients to have a primary care physician or medical home. A vast majority of our patients make the emergency room their medical home. There is no comprehensive model here to help reduce the major healthcare complexities that SCD patients encounter.

It is because of these challenges and more that H.R. 1807 is so crucial for the sickle cell community. Reauthorization is needed to assure program stability, establish more effective care coordination, set in motion a model of care, and allow for a broader reach into areas of the country where people with sickle cell disease are not adequately served. This legislation will allow States to receive Federal funding for patient counseling, education initiatives, and community outreach programs, set the groundwork for 25 sickle cell treatment centers across the country to treat our patients, support the continuance of a national coordinating and evaluation center, allow the Centers for Disease Control to establish and continue its surveillance program.

Through this initiative, we are hopeful that data collected would help us to understand and improve current estimates about the incidence and prevalence of sickle cell disease. Distinguished leaders, I humbly stand -- and I know I am sitting -- before you as an advocate. No, I do not have sickle cell disease. I am not personally affected by it. I do not have anyone in my family with it, but I am an advocate.

I, like you, believe that every American deserves equitable quality of life. Individuals with sickle cell disease deserve better treatment. They deserve better access to care, and more importantly, they deserve a better quality of life. So will you stand with me and support this legislation? It can and it will change many lives for the better. Thank you.

[The prepared statement of Ms. Banks follows:]

******** INSERT 1-3 ********

Mr. Pitts. The chair thanks the gentlelady and now recognizes Dr. Morrison 5 minutes for your summary.

STATEMENT OF R. SEAN MORRISON, M.D.

Dr. Morrison. Chairman Pitts, Ranking Member Green, and members of the Energy and Commerce Health Subcommittee, good morning, and thank you for the opportunity to address H.R. 3119, the Palliative Care and Hospice Education and Training Act. My name is Sean Morrison, and I am professor and vice chair of geriatrics and palliative medicine and director of Palliative Care at the Mount Sinai Health System New York City. I am a former president of the American Academy of Hospice and Palliative Medicine, and I am here today representing the Patient Quality of Life Coalition, a group of over 40 patient, provider, and health systems focused on improving the quality of life for persons living with serious illness and their families. I would also like to thank Representative Engel, a fellow New Yorker, for his continued leadership, and the 33 other bipartisan members of this committee who have signed this bill.

As a practicing physician, health services researcher, and teacher, I am acutely aware of the challenges faced by the seriously ill in this country. Multiple studies have demonstrated that inadequately treated systems, fragmented care systems, poor communication between patients, families and their physicians, strains on caregivers, and escalating healthcare use all characterize the

experience of living with a serious illness in this country. Five percent of seriously ill Medicare beneficiaries account for over 50 percent of spending, and contrary to the popular perception, only 11 percent of these persons are in the last year of life. The majority live for many years with progressively debilitating illness that interferes with their quality of life and ability to work and live independently.

Palliative care is team-based care: doctors, nurses, social workers, and chaplains, focused on relief of pain and other symptoms and support for the best quality of life for patients and families in the setting of a serious illness. It should be provided at any age at the time of diagnosis of a serious illness and concurrently with all other appropriate medical treatment, including those directed at cure and life prolongation. Palliative care has been shown to enhance quality of life, doctor-patient family communication, satisfaction with care, reduce healthcare costs, and in cancer, improve survival. Over 95 percent of mid- to large-size hospitals now have palliative care teams, and palliative care is being rapidly integrated into the nonhospital settings.

Yet three major challenges remain if palliative care is to become universally accessible and, indeed, inserted into the genome of American medicine. First, based on a recent national survey, over three-quarters of patients and families who could benefit from palliative care don't know what it is and thus cannot request it when it would be most beneficial. Yet when read a definition of palliative

care, more than 90 percent said they would want it for themselves or their family members and that it should be universally available throughout the country. Targeted educational efforts to increase patient, family, and provider awareness about palliative care and its benefits are appropriately recommended in H.R. 3119.

Workforce shortages prevent patients from accessing palliative care. There are simply too few palliative care specialists to meet the needs of the population. The 134 existing palliative medicine fellowship programs graduate fewer than 300 new doctors a year, less than a 10th of what is needed. Because palliative care was recognized as a subspecialty, after the Balanced Budget Act of 1997 limited the number of Medicare-supported residency spots, training in palliative medicine is now supported only by private sector philanthropy and variable and inconsistent institutional support.

H.R. 3119 would support specialist training in palliative care, palliative care education for students and trainees, and mid-career training in the core palliative care knowledge and skills for nonpalliative-care practicing healthcare professionals.

Finally, the knowledge base to support palliative care is inadequate. Treatment for symptoms, such as breathlessness, fatigue, itching, and pain, are primitive compared to the science underlying most disease treatments. Despite four reports from the Institute of Medicine calling for major Federal investment in palliative care research, a recent study found that less than 1/100th of a percent of the NIH budget is focused on improving quality of life in the setting

of serious illness.

I struggle daily with the fact that opioids with all of their attendant risks remain the most effective treatment for my patients in severe pain. H.R. 3119 would require the Director of the National Institutes of Health to expand and intensify research specific to palliative care.

To close, H.R. 3119, the Palliative Care and Hospice Education and Training Act will help address the barriers preventing all Americans from enjoying the highest quality of life in the setting of serious illness. I would like to again express my sincere thanks for the opportunity to address this important issue and legislation on behalf of the Patient Quality of Life Coalition with you this morning. Thank you again.

[The prepared statement of Dr. Morrison follows:]

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Mr. Pitts. The chair thanks the gentleman and now recognizes Dr. Marino 5 minutes for your summary.

STATEMENT OF BRAD MARINO, M.D., MPP, MSCE

Dr. Marino. Good morning. My name is Brad Marino. I am a pediatric cardiologist at Ann & Robert H. Lurie Children's Hospital of Chicago. I am a professor of pediatrics at Northwestern University Feinberg School of Medicine. I am the chair of the Medical Advisory Board for the Pediatric Congenital Heart Association, and I currently chair the Council for Cardiovascular Disease in the Young for the American Heart Association.

Thank you very much for the opportunity to offer testimony today in support of H.R. 3952, the Congenital Heart Futures Reauthorization Act of 2015. I wish to thank Chairman Pitts and Ranking Member Green for holding this hearing and Representative Bilirakis and Representative Schiff and the dozens of congressional cosponsors for the bipartisan effort to build upon existing programs which promote lifelong research, track epidemiology, and raise awareness for congenital heart disease, or CHD, the most common birth defect.

On behalf of Lurie Children's, the Pediatric Congenital Heart Association, the American Heart Association, the Children's Heart Foundation, and the Adult Congenital Heart Association, and the millions of individuals with CHD, I want to offer my strongest support for this very important legislation. Lurie Children's, the sixth

ranked children's hospital nationally by U.S. News and World Report, is the largest provider of pediatric specialty care in Illinois, as well as serving children from all 50 States and 46 countries, many of whom have congenital heart disease.

As a practicing pediatric cardiac intensivist, epidemiologist, and outcomes researcher, for more than 20 years, I have borne witness to the catastrophic results of CHD on affected children and their families that last a lifetime. Critical information about the epidemiology of CHD, the effectiveness of treatments, and lifelong outcomes is seriously lacking at best and nonexistent in specific areas such as secondary sequelae of CHD.

Over the last several decades, tremendous advances in care have dramatically reduced mortality rates for children with the most complex congenital heart disease and increased life expectancy of adults with CHD. In the absence of U.S. data, extrapolation of Canadian data suggests that there are currently more than 2.4 million individuals living in the United States with CHD, half of whom are adults. However, while survival has improved, the reality is that complex CHD and its treatments may result in significant cardiovascular complications and organ-specific comorbidities, including kidney and liver disease and brain injuries, that significantly impact health status, physical, and psychosocial functioning, and quality of life.

Early intervention for CHD is not a cure, underscoring the need for those with CHD to have lifelong care by expert providers. We need to better understand and improve the transition from pediatric to

specialized adult cardiovascular care. Estimates suggest that less than 25 percent, one out of four, adults with complex congenital heart disease are receiving appropriate subspecialty care. People born with CHD require lifelong, costly specialized cardiac care. As a result, healthcare utilization among the CHD population is disproportionately higher than the general population.

It is estimated that compared to the medical costs of care for the general population, the medical costs for individuals with CHD are 10 to 20 times greater. Around half of all dollars spent on pediatric CHD-related inpatient admissions is paid by Medicaid.

To improve care and reduce costs, it is essential that Congress enacts legislation supporting increased understanding of CHD across the lifespan. The Congenital Heart Futures Reauthorization Act of 2015 calls for the robust public health research and surveillance that will help us better understand and improve long-term outcomes for the more than 40,000 babies born each year with CHD.

Since the enactment of the Congenital Heart Futures Act of 2010, Congress has appropriated nearly $15 million to support CHD activities at the CDC, which has led to the standardization of research methods and an increased understanding of the public health burden that CHD poses. Continued Federal investment is desperately needed to better understand CHD across the lifespan, improve outcomes, and reduce costs. The Congenital Heart Futures Reauthorization Act of 2015 does just that. This legislation assesses the current state of biomedical research for CHD across the lifespan by directing the NIH to provide

a status report on its current research on CHD. This will improve an understanding of the causes of CHD and drive innovation and effective treatments for CHD and related disease processes. H.R. 3952 expands public health research on CHD by directing the CDC to plan, develop, and implement a representative cohort study. The data from this cohort will help to describe basic U.S. demographics of CHD, assess healthcare utilization, and develop evidence-based practices and guidelines for CHD care, eliminating our reliance on statistics from Canada to describe the burden of CHD in the United States.

This bill also directs the CDC to establish and implement an outreach, education, and awareness campaign, and ensuring that those with CHD receive appropriate care across their lifespan. With this critical education campaign, individuals with CHD and their families will better understand their lifelong healthcare needs and the necessity of receiving appropriate lifelong specialized cardiac care.

Congenital heart disease is common. It is costly, and it is a critical public health issue. In enclosing, on behalf of the Ann & Robert H. Lurie Children's Hospital of Chicago, the Pediatric Congenital Heart Association, the American Heart Association, the Children's Heart Foundation, and the Adult Congenital Heart Association, I urge you to take swift action to enact H.R. 3952, the Congenital Heart Futures Reauthorization Act of 2015. It is essential that Congress pass this legislation to provide improved care, outcomes, and quality of life for the millions of individuals in the United States with CHD.

Thank you for your time and consideration.

[The prepared statement of Dr. Marino follows:]

******** INSERT 1-5 ********

Mr. Pitts. The chair thanks the gentleman.

And I will begin the questioning and recognize myself for 5 minutes for that purpose.

Dr. Leffert, we will just go down the line. Thank you for highlighting the impact that metabolic diseases, such as diabetes, have on our healthcare system. Can you talk specifically about some of the issues or problems with the way the Federal Government currently administers programs for diabetes and related diseases that the commission is intended to address?

Dr. Leffert. Thank you, Mr. Chairman.

We have over 30 agencies across the Federal Government landscape that are engaged in either diabetes research or clinical care. And over the 5-year timeframe from 2007 to 2012, there has been a 48 percent increase in the money spent on diabetes care and lost productivity due to diabetes. The commission will recommend programs and activities to affect the quality of life, productivity, cost to society of patients with diabetes, prediabetes, and related conditions. Additionally, there are examples of inconsistent and sometimes counterproductive policies emanating from Federal agencies that reflect a lack of communication and coordination in the administration of Federal diabetes activities. The commission is intended to provide a venue that brings these agencies to the table on a consistent basis to improve upon those issues.

Mr. Pitts. Thank you.

General Dean, in your written testimony, you state that the

incidence of underage drinking has been going down in each year among 8th, 10th, and 12th graders. If this is true, why do we need to continue investment in this STOP Act, and what work is still left to be done?

Mr. Dean. In fact, it is true, but there is much work that needs to be done to address underage drinking in the country. And we believe that the STOP Act has been a catalyst for these improvements, and without it, we don't believe these improvements will continue. But we need to keep the pressure up to maintain these efforts. Despite our progress, in response to our 2015 survey of coalitions, alcohol continues to be the number one problem they face in their communities, and also we know that students that are underage in universities are significantly abusing these as well. The restructuring of the STOP Act will cause our coalitions to work directly with higher institutions of education to address these problems as well.

Mr. Pitts. Thank you.

Ms. Banks, can you elaborate on the biggest barriers to quality health care for those suffering from sickle cell disease?

Ms. Banks. Well, I think some of the largest barriers for individuals with sickle cell disease, first and foremost is the lack of access to care. As mentioned, there are a shortage in primary care physicians, and therefore, our patients do not have a medical home, which means that they frequent the emergency room often, so that is a huge, a huge deficit for us. Also, there is no comprehensive model of care and what our patients lack and what we do not have in our community is a care coordination program where someone is actually

providing care coordination with our patients. Our patients are born with sickle cell disease, so we know throughout the lifespan that they are going to have it. There is no cure for it. So the goal would be for us to coordinate their care throughout the lifespan, and that is what is really missing in the sickle cell community.

Mr. Pitts. Thank you.

Dr. Morrison, how does palliative care specifically help those individuals and families of those who are suffering from a serious but not necessarily terminal illness?

Dr. Morrison. Living with a serious illness in this country, such as congestive heart failure, chronic obstructive pulmonary disease, cancer, Alzheimer's disease, is associated with a number of distressing symptoms -- pain, breathlessness, fatigue, nausea, anxiety -- which people live with on a daily basis. It provides an enormous strain on family caregivers, who often give up their jobs, their work, to care for a seriously ill older relative. Palliative care addresses these needs by providing an added layer of support to patients, their families, and doctors. It treats the pain and symptoms of a distressing illness. It helps facilitate communication and provides support to patients and families. It addresses psychological, emotional, and spiritual needs, and it allows them to obtain the best quality of life possible in the setting of a serious illness. And it is absent from our American healthcare system at this point.

Mr. Pitts. Thank you.

Dr. Marino, why is it so difficult to retain patients in followup care for their congenital heart disease, and what does H.R. 3952 do to help change that?

Dr. Marino. So one of the programs that I have been spearheading at Northwestern is something called the cardiovascular bridge programs. So typically in the U.S. today, when you are 18 years and 364 days, your doctor will say: It has been great taking care of you. Here is the name of a doctor in the city. Have him call for the records. Good luck.

Only one out of four patients that need ongoing cardiovascular care actually get that cardiovascular care. What this bill is going to do is create awareness among patients and parents that when your child has surgery as a baby, it is not curative. There are ongoing specific cardiac issues. There are developmental issues, kidney and liver issues, that have to be dealt with as that child ages and then gets transitioned into adulthood.

In our bridge programs at Northwestern, we literally have a team of adult and pediatric providers, social workers, and advanced practice nurses that basically work with patients 16 to 26 to allow these patients to have a graded transition instead of an abrupt transition at 18 that will keep them in care.

Beside the awareness, by having the cohort study that is put in 3952, that the CDC would put together, we would know much more specifically which patients are at the highest risk for not following up, which patients are at the highest risk for having complications.

That will then tell us, of those patients that we know we need to follow up, which are the most critical to make sure they stay in care.

And then, lastly, with the NIH putting forth a status report on the biomedical research, there is so much research that still needs to be done on how best to care for these patients, what interventional procedures might result in a better quality of life as they transition from an adolescent to an adult. By having that new research and that priority for that research in place with NIH, we will be able to put new care models in place and new treatment models that will help these patients transition more effectively from adolescence into adulthood.

Mr. Pitts. The chair thanks the gentleman.

I now recognize Mr. Green 5 minutes for questions.

Mr. Green. Thank you, Mr. Chairman.

Dr. Leffert, diabetes can be effectively managed through evidence-based treatments, as well as through behavioral changes, including changes in diet, increasing physical activity. Some patients still experience devastating complications from diabetes, including blindness, kidney failure, and limb amputation. Why do these complications occur in spite of the availability of the treatments we have?

Dr. Leffert. Representative Green, the issue really is that we have a limited number of endocrinologists who are able to take care of patients with diabetes. We have a primary care base of physicians who take care of diabetes, but oftentimes, they are not all given the tools or the experience to be able to take care of these patients in

the appropriate way. They need a lot of help, and our commission bill would do that.

In addition, our patients need education. Education is the key because this is a self-managed disease, and this bill would also help that in relationship to many of the programs that are currently being projected by the National Diabetes Education Program, which gives patients education towards diabetes.

Mr. Green. Thank you. It sounds like this commission would help us explaining to physicians, you know, how we can treat diabetes, again, with medication. And I always tell people it is much better to have prediabetes than diabetes so that you can manage it much better. Thank you.

The STOP Act became law in 2006, and almost 30 percent of the underage individuals who were alcohol users and 19 percent were binge users that year. This legislation marked the first national comprehensive effort to combat underage drinking. And, again, I want to recognize my colleague and classmate, Congresswoman Roybal-Allard, for her diligent effort. And like I said -- before you were here, Lucille -- she has worried me about this bill for a number of months.

General Dean, can you talk about the progress you have made since 2006 and why reauthorization of these programs is so important?

Mr. Dean. Thank you very much, Ranking Member Green, for your interest, your leadership, and your support. We have made tremendous progress. Monitoring the Future cites that underage drinking percentages are down. They are the lowest they have been for years,

but we still need to continue to work diligently. And what this reauthorization is going to do is not only will we be able to provide enhancement grants to community-based coalitions that have been trained and understand how to tackle and resolve problems in their communities, but it is also going to give them a few dollars, allow them to work with higher education, colleges and universities as well, where we know there is a serious problem there too. And we think there are too many losses of life. Certainly, we can prevent that. We also can continue to tackle the violence and the unfortunate incidents that are taking place on our universities as a result of drinking, so there is still much work needed to be done, and we believe the reauthorization and the way it has been restructured will allow us to continue to make progress around this serious underage drinking problem.

Mr. Green. Thank you. Thank you for your effort on that.

Palliative care is a critically important aspect of healthcare system. It does not always garner the attention that it warrants.

Dr. Morrison, can you help this committee understand that palliative care, both from its impact on a patient's quality of life and the workforce involved, and how does this legislation improve the palliative care?

Dr. Morrison. Thank you for the question. Palliative care is a relatively new specialty. It began in the 1990s when a number of us said: Why do you have to be dying in order to have a good quality of life? And back before palliative care, the only real area that focused on improving patient's quality of life was hospice. And as

we all know, you have to have a prognosis of 6 months or less to be able to access hospice in this country.

So it is a relatively new specialty, and it is one of the fastest growing specialties in the United States, but we still have a workforce issue. We have one palliative medicine physician for every 13,000 people with serious illness, and this bill addresses this in three ways.

First of all, it does create a specialist workforce that will provide the research, the teaching, and take care of the most complex patients and families. But it also provides the core knowledge and skills of palliative care to those in training and those in practice. I spent 4 years at the University of Chicago, 3 years at New York Hospital Cornell Medical Center, another 3 years at Mount Sinai, and in that entire 10 years of education, had a 30-minute lecture about pain management that happened in my first year pharmacology course. And it dealt with how drugs like morphine are broken down in the liver and excreted in the kidneys. That was the extent of my education in how to treat distressing symptoms, and we have a generation of healthcare providers with that base fund of knowledge.

So this bill will address that as well by training those doctors, nurses, social workers, chaplains, who care for the seriously ill in the core knowledge and skills of palliative care: pain and symptom management, communication, care coordination.

And, finally, it addresses the evidence gap. We have all seen the problem in this country of inappropriate prescribing of opioids because we have a generation of doctors who do not know how to assess

pain, how to manage pain, how to appropriately use opioids, and how to identify the problems of addiction. I have never had a patient come to me in serious pain and say: I would like my pain treated and, oh, by the way, I would like to be addicted to the medication afterwards.

RPTR MELHORN

EDTR SECKMAN

[11:01 a.m.]

Dr. Morrison. That can be addressed through outreach, and it can be addressed through appropriate knowledge and teaching. And that is what this bill addresses as well.

Mr. Green. Mr. Chairman, thank you. And I have some questions we will submit. But our committee and the subcommittee has actually passed a number of opioid bills. And I think you are correct. We need to have training for the physicians who are actually prescribing, and hopefully, this bill along with the package of bills we passed out.

Thank you, Mr. Chairman. I yield back.

Mr. Pitts. The chair thanks the gentleman.

I now recognize the vice chair of the subcommittee, the gentleman from Kentucky, Mr. Guthrie, 5 minutes for questions.

Mr. Guthrie. Thank you very. I am going to try to get as many questions, so if answers could be kind of brief.

But first, Ms. Banks, I have a friend of mine whose son has sickle cell. And I didn't really know that much about it. Dr. Burgess has been helping me with it sitting here. But we hired him so he would be gainfully employed. And just working with his schedule was about my only experience with it.

So, with this bill, are there any other efforts existing within the sickle cell community that would complement this bill and allow

it to be more expansive to the patient population.

Ms. Banks. Absolutely. Currently, we are in the process -- and when I say "we," I mean SCDAA and many office treatment centers or hospitals -- are working with community health workers. So we have actually instituted what is called a community health worker program. What we feel like in the sickle cell community is it is going to take a concerted effort throughout the community. So we are utilizing not only the providers but also community-based organizations and utilizing community health workers to actually go into the field, find these patients, because a lot of our patients are lost, meaning they haven't been to a physician in a year or so. And that is not good for them and their health. And then not only are they finding these individuals, but they are getting them into a medical home. So the goal is that you find the patient, but then you enroll the patient or you help that patient find medical care.

In addition, SCDAA has launched a national patient registry, which is the first ever of its kind. It is a patient-powered registry. We know that it is long overdue in the sickle cell community. We know that it is going to help us to collect the data that we need. But also, along with collecting that data, this is patient-powered. So it allows the patient to communicate with the physicians. It allows the patient to actually manage their care via technology. And also it allows the patient to be up-to-date on treatments and research that is going on in the community for sickle cell patients.

Mr. Guthrie. Okay. Thank you very much.

Dr. Marino, great to see that Northwestern is doing good work. I am moving my daughter there Monday. So she will be on the Evanston campus. So, in your testimony, you mentioned the use of Canadian data. What type of U.S. data do we have, and why do have to use the Canadian data? I would just let you expand on that.

Dr. Marino. Mr. Guthrie, first, congratulations to your daughter. Northwestern is a very, very tough school to get into. So congratulations to her.

There is no data in the U.S. What we have is single-center data of very small numbers of individuals that we can't extrapolate to national data. And because the data is collected very differently at the different centers, with variable definitions that don't match, you can't take 10 or 15 centers and put the data together. Because the Canadians have a national health system, they actually have a national data set that allows them in a very specific way, like Denmark as well, to gather this longitudinal date on the congenital heart disease patients. So 3952 would specifically have the CDC create a cohort study in the United States that would follow this very high-risk complex CHD population over time to collect that similar data. We don't know if what we have in the U.S. is different than Canada or if it is the same. There is just no data.

Mr. Guthrie. Okay. Well, maybe on one of my visits over the next little while, I will be able to see what you guys are doing. That would be interesting to see.

So, General, I just want to ask you a question. And

congratulations on your service and obviously reaching one of the top ranks in the military. That says a lot about your ability. Why is training pediatric healthcare providers in screening -- let me start over. Why is training pediatric healthcare providers in screening, brief intervention, and referral to treatment important? And why is the provision on this being added to the STOP Act? And can you discuss how this new provision's authorization will work within the overall authorization for the bill?

Mr. Dean. Thank you for your question. It is a very important question. It is a, we believe, a significant change in the restructure of this reauthorization. And we are very excited about the inclusion of -- we call it SBIRT for pediatric healthcare providers. It is a strong complement to the universal prevention as it allows youth who have been misusing substances to be identified more readily and to get effective intervention in a larger number of community settings. We also know it is effective. And a 6-month followup with SBIRT participants found that heavy alcohol consumption was 39 percent lower among individuals who initially screened positive for hazardous drugs and alcohol use. So screening early, training pediatric providers to do this, we have found already it is reducing the consumption by young people.

Mr. Guthrie. Okay. Thank you.

And, Dr. Leffert, what are the expectations that the clinical care commission can establish within the next 3 years? I guess you have 3 seconds to tell me that. So I apologize.

Dr. Leffert. Well, as you know -- thank you for the question, Representative Guthrie. As you know, diabetes is a big issue, and there is a lot of issues going along with it but. But we would hope that the process would allow for federally funded research initiatives from the bench to the bedside so that patients could have access to 21st century cures and innovations, and that these would become more coherent and synergistic, and that there would be better communication and coordination among the agencies, specifically NIH, FDA, and CMS. The commission would also help focus the efforts of the government research community toward improving clinical care for people with diabetes and to slow the incremental rise in diabetes and its associated complications.

Mr. Guthrie. Thank you very much.

My time has expired, so I yield back.

Mr. Pitts. The chair thanks the gentleman.

I now recognize the ranking member of the full committee, Mr. Pallone, 5 minutes for questions.

Mr. Pallone. Thank you, Mr. Chairman.

I wanted to ask Dr. Morrison to focus on the palliative care legislation, you know, both the access to treatment but also the services available to those individuals to cope with their conditions. First, from diagnosis, what is the most common diagnosis for individuals who receive palliative care services?

Dr. Morrison. The common diagnoses are what we consider to be serious illness. So it is cancer, heart disease, advanced lung

disease, Alzheimer's disease and related dementias, and neuromuscular diseases such as Lou Gehrig's disease or amyotrophic lateral sclerosis. In children, it is really two large groups of diseases. One is obviously cancer, and the other is congenital or genetic diseases. And because of advances in pediatrics, we have a whole population now of kids who are living long, long periods of time. And that is wonderful. However, they are living with multiple symptoms and high caregiver burden on their families.

Mr. Pallone. Well, you mention symptoms. What are the most common symptoms that are treated with palliative care?

Dr. Morrison. They are what you would anticipate: pain, breathlessness, fatigue, nausea, anxiety. In children, it is primarily fatigue. And it is the one symptom for which we have really no effective treatments as of yet because of the lack of the evidence base and the lack of the research science.

Mr. Pallone. All right. Now, let me ask a couple questions about access. Do most people battling serious health conditions, such as cancer, have access to palliative care services, and what are some of the consequences for individuals with serious illness who don't have access?

Dr. Morrison. It is a very good question. What we know from a study actually we did earlier this year was that now 97 percent of mid- to large-size hospitals in the United States now have palliative care teams. And if we look at the Medicare population, about 75 percent of all Medicare beneficiaries who die live in an area where they could

potentially access palliative care. The problem is that those hospital teams are relatively small and, because they are still understaffed, see only a small proportion of the number of patients and families who could truly benefit. What we have seen in the past 3 years also, however, is the expansion of palliative care into the community, particularly in Medicare Advantage plans and commercial plans, which aren't limited by the fee-for-service structure of the traditional Medicare program. So we are seeing some very, very new and exciting models of care happening in the community, particularly in Tennessee and Nashville, as was said earlier.

Mr. Pallone. Well, in terms of increasing access to important services, how can we increase it? How does this bill help?

Dr. Morrison. I think it helps in three ways. The first is that, because palliative care is a relatively new specialty, most people don't know what it is. Again, a survey that we did with the American Cancer Society several years ago showed that about 80 percent of a national representative sample had never heard of palliative care and didn't know what it was. And yet, when we read a definition to them, over 90 percent said that this is what they would want for themselves and their families. Providers too don't understand palliative care and too often confuse it with hospice and end-of-life care, when the reality is palliative care is for everybody. It is not dependent on prognosis. And in fact, we provide it to people we expect to be cured. So there is an educational campaign awareness that needs to happen.

And the second issue is we need to address the workforce gap.

Every single clinician in this country who cares for somebody with serious illness needs to be able to treat pain appropriately, manage breathlessness. Talk to them about how a serious illness -- I have probably as much training, sir, as you in how to talk to somebody and break bad news that you have cancer. When I finished medical school, we had the same amount of training in terms of how to have that conversation. And we need to address that through our medical schools and our training programs and to physicians like me who are in practice. This bill will do this as well.

Mr. Pallone. Well, thank you. I am just trying to get in one question for General Dean about strategies for preventing underage drinking. I just want to learn more about the methods to prevent underage drinking. General Dean, what types of strategies and programs work best to prevent underage drinking, and what evidence is available to prove that these interventions work?

Mr. Dean. Okay. Thank you, Congressman. It is a great question. We believe that by mobilizing the entire community -- what I mean by that is all of the sectors in the community: you know, parents, teachers, youth, the police, business providers, faith community, civic business leaders all coming together. And we have built over the last 25 years a strategy, an academy type approach, to train the members of the community how to identify their problems, how to address their problems, and how to implement evidence-based strategies to reduce their problems. There have been evaluations done by the Office of National Drug Control Policy independent of CADCA that show that

when these communities have been trained, the results are significant. And we have great examples. In the interest of time, I will not cover them with you. But I do have several examples here where communities have reduced their underage drinking by large percentages, 20, 30, 40, 50 percent, using these methods.

Mr. Pallone. Well, through the chairman, if maybe we could ask him in writing to follow up with and give us those examples. Mr. Chairman, with your permission, he mentioned that he doesn't have the time to give some examples. So, with your permission, maybe we could have him follow up in writing and give us that information.

Mr. Pitts. I am sorry. I was talking.

Mr. Pallone. No, I know. That is all right. He wanted to give me some examples, but in the interest of time, he is not doing it. I was going to ask if he could do it in writing.

Mr. Pitts. Yeah. We will submit that to you in writing and ask you to please respond.

[The information follows:]

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Mr. Dean. I will be glad to. I have several examples of communities that have made significant progress, some exceeding 50 percent reduction using these community-based strategies to reduce underage drinking all across the country, both rural, urban, as well as suburban.

Mr. Pallone. Thank you.

Mr. Pitts. Very good. Thank you.

The chair now recognizes Dr. Burgess 5 minutes for questions.

Mr. Burgess. Well, thank you, Mr. Chairman.

And thanks to the panel for being here.

It has been a very interesting morning listening to you all.

Ms. Banks, let me just ask you, and I was struck in your testimony, both the written testimony and your testimony here this morning, you say it has been decades since there has been a new FDA-approved treatment for sickle cell. Is that correct?

Ms. Banks. Correct.

Mr. Burgess. So my recollection of Parkland Hospital in the 1970s is actually pretty much current therapy. Is that right?

Ms. Banks. Correct.

Mr. Burgess. You know, and I referenced this in my opening statement, this committee has spent a lot of time on a bill, H.R. 6, called Cures for the 21st Century. And although sickle cell -- and we tried not to have disease-specific parts of the bill, I mean, this just strikes me as one of those areas where the type of translational research that would go across the National Institute of Health or would

give the National Institute of Health Director much more discretion as to what they researched and what they funded, that this would be one of those areas.

You know, and I just went on clinicaltrials.gov to look for the current clinical trials in sickle cell, and there weren't as many as I thought there ought to be for a disease of this magnitude that is so pervasive in the community. I mean, is that a reasonable assumption I have made looking at clinicaltrials.gov?

Ms. Banks. Actually, you are correct. We are always wanting more research for sickle cell disease. I will say this.

Mr. Pitts. Poke your microphone.

Ms. Banks. Oh, I am sorry. I will say this. About 7 years ago, when I started the Sickle Cell Disease Association of America, we literally had about two pharmaceutical companies in the space for sickle cell disease, and today we with about 16. So it is looking up for sickle cell disease. Of course, we still have to get over that hurdle of getting individuals in those trials and going through that. But it is hopeful.

But I totally agree with you. Sickle cell disease has long been forgotten. And over 100 years -- this is probably one of the oldest diseases for its discovery out there -- for there only to be one drug for treatment -- and by the way, that drug is hydroxyurea. That drug was not approved for sickle cell disease. It is an actual cancer drug. So, really, when you look at those kinds of issues, it is long overdue in the sickle cell community.

Mr. Burgess. Yeah. And I appreciate your comments on that. And it is something we will keep an eye on in this committee because, of course, I am going to be optimistic that we are going to get Cures for the 21st Century done in this Congress. But there will also be an FDA reauthorization that takes place in the next Congress. And that is another appropriate place to focus on this.

General Dean, I want to ask you a question. It is probably not fair because it is not on the bill that you came to testify on. But in your role as the CEO of Community Anti-Drug Coalitions of America, I got asked a question by a constituent, and I didn't know the answer. And I was a little bit embarrassed that I didn't know the answer. And if you don't know the answer, it is okay. You don't need to be embarrassed. Perhaps you can point me in the direction that I need to go. There is a woman who came into my office. She had lost her son in a -- he was a pedestrian struck by a vehicle. He was in a crosswalk. The individual who was driving the vehicle was not issued a ticket or a citation. He did have alcohol in his system, but it was under the .08 limit in the State of Texas. But he also had a positive qualitative test for the active ingredient in marijuana. Okay. It seems to me that -- and obviously, this would be a State law, but does your group look at, now that there are more and more States that are providing a legal avenue for consumption of marijuana, does your group look at the additive multiplicative effects of drugs and alcohol? Do States need to perhaps reconsider what their limits are? This just struck me -- of course, it is a very tragic and unfortunate case. But

that just seemed like it was one of those things that cried out for something in addition to be done.

Now, law enforcement made -- you know, their position was, as far as laws of the State of Texas, we don't prosecute for having small amounts of marijuana in your blood. And this was a qualitative test, not a quantitative test, so we don't even know to what degree of intoxication there might have occurred from that, but from the alcohol standpoint, under the legal limit of intoxication.

Mr. Dean. To answer your question, Congressman, we do care about this issue very much. We do watch and observe what is happening in States that have, first, through citizen votes decreed that there was some -- that marijuana is medicine. It obviously has not gone through the FDA process for that to be done. So we watch that carefully. We also are watching the States where they have -- through citizens have passed it for recreational use. And we have seen, looking at data coming out of States like Colorado, Washington, and others, that there is a substantial increase in citizens, both young and old, driving under the influence of drugs versus alcohol. And in some cases, there are more impaired drivers on the streets these days in those locations from drugs than there are from alcohol.

So the law enforcement challenge is having the appropriate instruments and tests to test for it. It is not as simple as it is for alcohol. And, therefore, it becomes challenging for them to do that. So the answer is we are seeing the results. We are seeing the impact. We are concerned about it, and the law enforcement community

is extremely concerned about it.

Mr. Burgess. Well, I will have my office follow up with you. We may have further discussion about this. But you are the first person who has come to this committee who might know something about this. And I do want to follow up with you. And I would appreciate the opportunity to do so.

Mr. Dean. It would be our pleasure.

Mr. Burgess. And, Mr. Chairman, I also would ask unanimous consent, I have a 2013 article, but it is the most recent one I could find, "Current Management of Sickle Cell Anemia," and I would like to submit this for the record.

Mr. Pitts. Without objection, so ordered.

[The information follows:]

******** COMMITTEE INSERT ********

Mr. Pitts. The gentleman yields back.

The chair now recognizes the gentleman from North Carolina, Judge Butterfield, 5 minutes for questions.

Mr. Butterfield. Thank you, Mr. Chairman.

Ms. Banks, I want to come back to you for just a couple of minutes, if you don't mind. Ms. Banks, can you describe for me how diminishing Federal funding, including lack of funding for treatment centers, has made it more difficult for people with sickle cell disease to get the care that they need?

Ms. Banks. Sure. Of course, with every disease, especially with the complications in sickle cell disease, it is a challenge when you do not have the funding in place. Eventually, when the bill was first passed, because this is a reauthorization, there was a place in the bill where it said 40 treatment centers. To my knowledge, sickle cell only received 10 of those treatment centers or 10 of those treatment centers were funded. Because of that, our patients basically do not have a medical home. That is the reason why a lot of them frequent the emergency room. So, when you talk about diminishing Federal funding, you are looking at, where do our patients go for access to care? That is extremely, extremely important.

We are hoping -- in this bill, we ask for 25 treatment centers, because we wanted to be very realistic in our ask and we wanted those 25 centers to be in areas where there are high populations of individuals with sickle cell disease. We are hoping that that would provide some coverage. We know it will not for 100,000 patients, but

it would provide some coverage for our patients and somewhere to go.

I also want to make it -- it is very interesting, in comparable diseases, for instance, with cystic fibrosis, they have over 100 treatment centers. With hemophilia, I think they have over 40, 42. So, with sickle cell disease, only having 10 funded, you can see with 100,000 patients where we are at a huge deficit.

Mr. Butterfield. Is it true that African American children have higher rates of disease in trait? Is that an accurate statement?

Ms. Banks. Say that again.

Mr. Butterfield. That Black children, African American children, have higher rates of disease.

Ms. Banks. Of sickle cell disease?

Mr. Butterfield. Yes, of sickle cell disease.

Ms. Banks. Yes.

Mr. Butterfield. Yes. And what proportion would you say of African American babies are screened for this disease at birth?

Ms. Banks. Well, actually, it is mandatory in every State. So, right now, every State screens for sickle cell disease when you are born.

Mr. Butterfield. It is a Federal mandate or a State mandate?

Ms. Banks. It is Federal.

Mr. Butterfield. Yes. All right. Are there any barriers that prevent babies from being screened for sickle cell? Are there any barriers that would prevent that from happening at birth? Or is it completely uniform across the board?

Ms. Banks. To my knowledge, it is completely uniform across the board.

Mr. Butterfield. All right.

Ms. Banks. Our issue, Congressman Butterfield, is that, years ago, when sickle cell was very prevalent and people heard about it, it was because babies were dying. And so, because of treatments, because of the newborn screening, babies are living well into adolescence. Our issue now is transition, and where do you go after you are 14, 15 and you begin to transition into young adult care? That is where we are having the shortage of adult hematologists or adult primary care physicians for those individuals. So now the challenge in sickle cell disease is where our babies are getting better, they are living through teens and young adult, and they don't have a place to go. So when you go to college, when you get to that college age, where do you start? I was talking to my chief medical officer, and it is interesting because there are individuals 24 and 25 years of age still going to pediatric physicians, a hematologist, because they do not have an adult physician that would treat their disease in a system in managing their disease.

Mr. Butterfield. Would you discuss the barriers, if any, facing African Americans from being screened or receiving treatment for sickle cell disease?

Ms. Banks. I think the barriers for African Americans, particularly -- or anyone with the disease pretty much is, again, the lack of a medical home. Our patients have been stigmatized mainly

because the key issue is pain. And if you are frequenting the emergency room for pain, what are you going to be classified as? For most, our patients feel as if they are ostracized because when they go in, they are going for drugs. And it is because we do not have any drugs for treatment of the disease that we are treating our patients with opioids. So that is a huge barrier in the African American community. But it is a huge barrier in the sickle cell community as a whole.

Mr. Butterfield. Thank you. You are very kind.

I yield back, Mr. Chairman.

Mr. Pitts. The chair thanks the gentleman.

I now recognize the chair emeritus of the full committee, Mr. Barton, 5 minutes for questions.

Mr. Barton. Mr. Chairman, I don't have any questions, and I am late arriving. So I am going to yield to the members who have been here.

Mr. Pitts. I recognize the gentleman from Florida. You are recognized for 5 minutes.

Mr. Bilirakis. Thank you, Mr. Chairman.

I appreciate it. Thank you, Mr. Chairman.

Again, I want to thank Chairman Pitts and Ranking Member Green for holding this very important hearing and including my bill, the Congenital Heart Futures Reauthorization Act. I appreciate it so very much. This legislation provided a 5-year reauthorization to the underlying law that I coauthored back in 2009. The Congenital Heart Futures Reauthorization Act will continue the CDC surveillance

program, continue to provide NIH grants for further congenital heart disease research, and require NIH to report on their ongoing research efforts. Congenital heart disease is the number one cause of birth defects related deaths. Twenty-five percent of children born with a congenital heart defect will need heart surgery or other interventions to survive. An estimated 2 to 3 million people are living with CHD. And individuals with CHD have an ER visitation rate of three to four times higher than the general population. The Congenital Heart Futures Reauthorization Act will continue our commitment to monitoring and increasing the available research and helping people born with a congenital heart defect. I would like to ask unanimous consent, Mr. Chairman, to introduce these letters of support: the Pediatric Congenital Heart Association, a letter from the Adult Congenital Heart Association, and a letter from the American Society of Echocardiography. I would like to ask unanimous consent.

Mr. Pitts. Without objection, so ordered.

[The information follows:]

******** COMMITTEE INSERT ********

Mr. Bilirakis. Thank you very much.

And I have a couple questions for Dr. Marino. Dr. Marino, what are the biggest challenges facing children and adults with CHDs as they age, and how will the Congenital Heart Futures Reauthorization Act help meet these challenges?

Thank you again, sir, for testifying today.

Dr. Marino. Congressman, thank you very much. We greatly appreciate your support.

It is a great question. Simply put, you know, when you have your surgery as a baby, you are not cured. And we know that these patients have specific neurodevelopmental issues that come from brain injury from when they had their surgery as a baby. We know that they have specific cardiovascular complications. Many of them go on to heart failure and need heart transplantation. They might need a ventricular assist device, mechanical support device. They often have abnormal heart rhythms. They often have decreased exercise function. These patients will also -- many of them have kidney or liver injury from their original therapies when they were a baby.

So, with this complex medical milieu of multisystem organ failure, they then now need to transition from an adolescent care model to an adult care model. You have heard from several of the other witnesses who are testifying today that there is lack of adult providers who can care for these types of patients that survive the childhood illness and then now move on to adult care. Adult congenital heart disease physicians are in -- we have the same dearth of care providers.

You have heard about palliative care and sickle cell disease. While there is now an accreditation for adult congenital heart disease care, there are still very few adult congenital heart disease care certified individuals nationally.

And then probably the last part which we discussed a little bit earlier was that, right now, there is no specific means by which we transfer these high-risk complex patients into adult care. And if you just hand off a patient at age 18, it is very unlikely, actually, that they are going to get followup care. And what we know -- and I want to focus on cost for a second -- if you get patients into appropriate followup care and you minimize secondary complications as adult congenital patients, you will lower overall costs to the system. And given that more than 50 percent of these patients will be cared for through Medicaid as children and then Medicare as adults, if we can find ways to transition them better, not lose three out of four patients during that transition process, it will likely lower the overall costs for these 2.4 million individuals nationally who survive with adult congenital heart disease.

Mr. Bilirakis. A very good point. Thank you so much.

Next question, the Congenital Heart Futures Reauthorization Act specifically calls for a cohort study. How does this differ from current surveillance techniques being used to study CHD, and why is this needed?

Dr. Marino. So, if you look over the last 20 years, there are lots of individual center studies trying to benchmark how these

patients are doing. They don't talk to each other relative to a data standpoint. I might be -- when I was at Harvard, working at Boston Children's Hospital or Children's Hospital Philadelphia or Cincinnati Children's or now at Lurie Children's during periods of my training and now my faculty positions, the data that is collected for these individual studies are all quite different. The definitions used to codify the patients and codify the complications that we have talked about are very, very different. So I can't take 10 different studies from 10 different centers and pull them together into a cohesive whole.

What 3952 will allow is for the CDC for the first time in the United States -- and by the way, this has been done in at least a dozen other countries around the world -- take the U.S. population, start collecting data at dozens of centers with the same variables, the same data set, and then follow them longitudinally, not just over 2 years, hopefully over decades, for us to get a much better sense for, what is the true incidence and prevalence of these complications that I have alluded to? What are the impacts of treatments that we then bring into the care models for these patients nationally? And then, more importantly, when it comes to transition, how do we best predict who is not going to have effective transition, who will, and then get the supports in place in adolescence to make sure we don't lose three out of four of these patients. Because I can tell you, in my work in Northwestern, there are literally dozens and dozens of patients each year that walk into us at Northwestern Memorial Hospital, who have been out of care, cardiac care, for 5 years, 10 years, who literally are

near death. And I know for a fact if they had actually had appropriate transition and actually stayed in care, they likely would have survived multiple more decades with a great quality of life.

Mr. Bilirakis. Well, thank you very much, doctor.

I want to thank the entire panel for their testimony.

And I yield back. I appreciate it.

Mr. Pitts. The chair thanks the gentleman.

I now recognize the gentlelady from Illinois, Ms. Schakowsky, 5 minutes for questions.

Ms. Schakowsky. Well, first, let me just apologize. It is hard to be everywhere at once. And I am really -- I was looking forward to hearing from you. And I want to thank you so much for being here, all of you.

I want to say I am proud to see that Dr. Marino is here from Lurie Children's Hospital, and I just want to acknowledge the unparalleled care that you provide for not just the children of Chicago but many who come to the hospital.

I have really focused for much of my public career, both in the Illinois legislature and now here, on improving senior citizens' access to health care. Along with my colleague Doris Matsui, I have served as the co-chair of the House Seniors Task Force. Given that 10,000 people turn 65 every day, it is imperative that we really work to address the specific health needs of seniors.

So, Dr. Morrison, let me focus on that. I am interested in hearing how the aging of our population is going to affect the need

for palliative care services moving forward, and by the way, you might want to distinguish between hospice and palliative care as you talk. Specifically, I am interested in hearing more about a statement you included in your written testimony that says, quote: "Over the next decade, most healthcare professionals will be caring for seriously ill older adults and their families with multiple chronic conditions, multiyear illnesses, and intermittent crises interspersed with periods of relative stability," unquote. So how is this going to affect the need for palliative care services among the population, this population, as well as a workforce trained in palliative care?

Dr. Morrison. Thank you, Congresswoman.

And as a geriatrician, thank you so much for your work for older adults in this country.

Let me take this in two ways. First, let me clearly differentiate between hospice and palliative care. Hospice was started in this country in the 1970s really as an alternative to life-prolonging curative treatment when it was recognized that many people near the end of life were experiencing distressing symptoms and very high care needs. And it has been a wonderful system of care since 1972, and even more so since Medicare covered hospice in 1982.

The problem with hospice is that you have to be dying to access it. And you to have a predictable prognosis of 6 months or less. And for those of us who began in palliative care, the question was, why should you be dying to have efforts focused on enhancing your quality of life?

When we look at the aging of the population, as you pointed out, it is the fastest growing segment in the United States. And for most of us, the time after the age of 65 or 70 is going to be many, many years of a very good quality of life. It will be time to integrate our work and life experiences. It will be time spent with our children and our grandchildren. But most of us, those of us who aren't killed crossing the street or have a sudden death, will develop a series of chronic ongoing progressive illnesses: heart disease, lung disease, even cancer for which we have transitioned many cancers into chronic illnesses. And as we age, we will have more and more of those: diabetes, frailty, multiple chronic conditions. And the data that we have now suggests that most of us will spend at least 7 years of our life in that state. And the data that we have nationally suggests that 70 percent of older Americans with a serious illness have three or more distressing symptoms on a daily basis. And we can do better.

The last years of our life, the last 5, 10 years, should not mean living with daily symptoms. It should not mean tremendous burdens on our children and our grandchildren to care for us. And it should not mean bankrupting Medicare to care for those. And palliative care, as a relatively new specialty, has demonstrated that it meets all those needs.

First of all, we have a wealth of data that palliative care teams improve symptoms. They make people feel better and their quality of life better. Secondly, it improves caregiver well-being and reduces burdens on caregivers. And, thirdly, by really providing the right

care to the right people at the right time, it reduces costs largely by providing that added layer of support in caring for people where they want to be cared for, in the home. In New York City, if my 85-year-old patient falls in the middle of the night and his wife can't get him up and he is struggling to breathe because of heart failure, right now, she calls a doctor's office. And when you call the doctor's office in New York City, what do you get? If this is a medical emergency, please call 911. And maybe you will get a voice at the end of the phone. If you call our palliative care team, you get a real person at the end of the phone. You may get somebody to come into the home. And you will have in place a plan to deal with predictable crises for older adults. That is the added layer of support that palliative care can provide to our healthcare system.

Ms. Schakowsky. Perfect. Thank you.

Dr. Morrison. Thank you.

Mr. Pitts. The gentlelady yields back.

The chair now recognizes the gentleman from Missouri, Mr. Long, 5 minutes for questions.

Mr. Long. Thank you, Mr. Chairman.

And, Dr. Morrison, how long has palliative care been around?

Dr. Morrison. Palliative care really developed as a specialty in about the mid-1990s, as I said, when we had this lightbulb go off that said: You don't have to be dying to have good quality of life.

But it only became a sub-specialty in 2008. So it has really only been since 2008 that the American Board of Medical Specialties has

recognized palliative care as a specialty. And so it is a very young field.

Mr. Long. My mom passed away in 2009. And I remember that when they came in and said, "We need to talk about palliative care," that was the first that I had really heard about it.

My series of questions are for you, Dr. Morrison. They focus on the care and support needs of individuals with Alzheimer's disease and other dementias. Could you elaborate on how palliative care could benefit people with Alzheimer's?

Dr. Morrison. Yes. Absolutely. As you know, the prevalence of Alzheimer's disease is increasing rapidly in the United States, largely as we have made tremendous progress in treating other diseases. Alzheimer's disease fits in many respects perfectly within the paradigm of palliative care. It is a multiyear illness. Families, as cognitive status declines, patients are more and more dependent upon their families. It is a disease that is associated with a tremendous symptom burden. All of the diseases that people had before Alzheimer's disease, their osteoarthritis, their heart disease that causes breathlessness, their lung disease, don't go away in the setting of Alzheimer's disease. What happens, though, is people can't tell you that they are breathless. They can't tell you that they are in pain. They can't tell you that they are hungry because of cognitive impairment. And so the suffering continues, but the suffering continues silently.

It is also a disease that has periods of stability where people

will be the same for long periods of time and then there will be a crisis, an infection, a pneumonia, a urinary infection, a pressure ulcer. And so it doesn't fit well within our current model of hospice because people with Alzheimer's disease aren't dying quickly. They are actually living for a long period of time. And what they do is they need support, and they need then crisis intervention, which palliative care can provide, and then ongoing support after that throughout the course of that illness. And, as importantly, Alzheimer's disease is not just a disease that affects the patient. All of us who have had a loved one with dementia or know somebody know that it extends to the family as well, and that the burden on families is almost as great as the patient itself, and that, as a specialty, palliative care focuses on both the patient and the family as the unit of care.

Mr. Long. Okay. Thank you. My aunt passed away from Alzheimer's about 6 weeks ago. So I can relate to everything you are saying there.

How easy is it for individuals to gain access to palliative services today? Second part, are there enough providers offering these services across different settings? And are there enough new providers being trained in this space to meet patient needs?

Dr. Morrison. Moderately easy, no, and no. And let me elaborate.

Mr. Long. Okay.

Dr. Morrison. The first is that we have built over the past 20 years, largely because of private sector philanthropy and investment

in infrastructure to support the development of palliative care. So, right now, 95 percent of our mid- to large-size hospitals have palliative care teams. And over two-thirds of all American hospitals have that infrastructure in place.

The issue is, as you pointed out, it is the workforce, that we actually don't have enough providers to be able to provide those services to everyone in need. And we really need two things. First of all, we need a specialist workforce not to take care of everybody with serious illness. That will never happen, and that should not be our goal. We need specialists to teach, to do the necessary research, and take care of the most complex patients and their families. And that is what the provisions of 3119 provide.

But, as importantly, we need to train every clinician who cares with somebody with serious illness in the core knowledge and skills of palliative care so that every doctor in this country knows how to treat pain effectively, every nurse knows how to communicate serious illness to somebody, and we have a care system that can provide that added layer of support for that very small but very expensive and very vulnerable patient population.

Mr. Long. Lastly, I would like to know, how do the needs differ of the older patients from the needs of younger patients as relates to providing palliative services, and do current training opportunities address these differences?

Dr. Morrison. It is a very good question. For most younger adults, most younger adults are typically living with a single illness.

Is it cancer? Heart disease? For children, cystic fibrosis. For older adults, it is much more complex, because most of us, when we age, will develop multiple chronic conditions that all intersect and all affect our quality of life. So it is not just cancer. It is cancer. It is heart disease. It is debilitating arthritis. It is diabetes. And it is both cognitive impairment, Alzheimer's disease, and often functional impairment, difficulty walking. So it is a much more complex population in many respects. I think what we have done very well within our field is the collaboration with geriatrics. The recognition that we will never have enough geriatricians, we will never have enough palliative care physicians to treat the population, the older adult population that need, and it requires a collaboration and for us to break out beyond specialist-level care to think about population-related care. And that is one of the reasons that 3119, the bill before you, is modeled after the very successful Geriatric Academic Career Awards. Because that was such a good model for improving access to care for --

Mr. Long. Speaking of 3119, that is how many minutes I am past time. So I yield back.

Dr. Morrison. I apologize, sir.

Mr. Pitts. The chair thanks the gentleman and now recognizes the gentleman from California, Mr. Cardenas, 5 minutes for questions.

Mr. Cardenas. Thank you very much, Mr. Chairman. And thank you for having this important hearing. First, I would like to recognize and thank my colleague Lucille Roybal-Allard for championing the

legislation H.R. 1717, which is part of this hearing today, the Sober Truth in Preventing Underage Drinking Reauthorization Act. It is unfortunate that, being on Appropriations, you are not allowed to be on Energy and Commerce.

But thank you, colleague Lucille Roybal-Allard, for being here and for introducing that great bipartisan legislation.

My questions today are based on diabetes. And I would like to ask some questions to Dr. Leffert. If you don't mind explaining to us what prediabetes is and how it increases the risk of an individual developing type 2 diabetes.

Dr. Leffert. Thank you, Congressman.

Prediabetes is the process of developing diabetes but before that happens. So the process -- the genetic and environmental process results in a situation where what we call glucose intolerance or impaired fasting glucose. Both of those conditions are what we now have termed prediabetes. The issue with prediabetes is that prediabetes is a surrogate for cardiovascular disease. So, in people who have prediabetes, the risk for cardiovascular disease goes up, and then the disease process then may progress on to type 2 diabetes. So it has both an effect in and of itself and also as a progenitor towards type 2 diabetes. The data, I think, is that about a third of the patients will go on to type 2 diabetes, about a third of the patients will remain prediabetic, and about a third of the patients will regress if they start with diet and exercise. And so the main issue in prediabetes for our population and why it is such a huge issue is because

of the fact that it is associated with obesity and genetic factors, particularly among populations, like African Americans and Hispanics, in our country.

Mr. Cardenas. And with proper education and cooperation with their health providers, et cetera, a person can decrease their chance of going from prediabetic to developing type 2 diabetes?

Dr. Leffert. That is absolutely correct. And I think that should be a big push of what we are doing in our healthcare prevention, meaning keeping people at the level of prediabetes or moving backward would be the most important aspect of what we do. And we can do that through a recognized approach towards nutrition therapy, towards dietary therapy, towards exercise. And there have been programs that have been done through the diabetes prevention program that have been successful in doing that particular thing itself.

Mr. Cardenas. Okay. How can the commission improve our ability to reduce the development of diabetes among individuals with prediabetes?

Dr. Leffert. Well, I think, again, it is a coordination issue. I think our Federal Government has a number of different agencies that are all working in somewhat in silos. And I think our commission would allow us to have all of the organizations, including the private sector, industry, and other organizations together, to be able to coordinate that effort and prevent the onset of diabetes if we have people who have prediabetes.

Mr. Cardenas. Now, obviously, there is a quality-of-life issue

for somebody to not develop into having type 2 diabetes. But what quantifiable numbers when it comes to dollars would be saved if we were more successful in our efforts and coordinated better like you just described? Are we talking just a few million dollars a year to our economy, or are we talking billions of dollars?

Dr. Leffert. I think we are talking more like billions of dollars because I think the issue, when we go from prediabetes to diabetes and the hospitalizations that are associated with diabetes, the complications of diabetes related to kidney disease, heart disease, eye disease, is astronomical, and I think we could save a large amount of money of our Federal budget related to that.

Mr. Cardenas. So diabetes-related illnesses like you just described I would imagine over lifetimes of tens and hundreds and millions of people would actually cost us trillions of dollars. Wouldn't it?

Dr. Leffert. Well, I think, right now, as Chairman Pitts said in his opening statement, one in three dollars of the Medicare budget is spent in diabetes.

Mr. Cardenas. So it is in the trillions.

Dr. Leffert. It is a very, very significant amount of money that is being utilized in that regard.

Mr. Cardenas. Thank you. I yield back.

Mr. Pitts. The chair thanks the gentleman.

And I now recognize the gentlelady from Indiana, Mrs. Brooks, 5 minutes for questions.

Mrs. Brooks. Thank you, Mr. Chairman.

In my home State of Indiana, over 750,000 Hoosiers have type 1 or type 2, and nearly 2 million of about 6-1/2 to 7 million Hoosiers have prediabetes. And so we know it is taking an immense toll on our State and on the Nation's healthcare system. But yet you talked about some innovations, continuing glucose monitoring and artificial pancreases. Can you tell me, Dr. Leffert, how the new treatments, new devices that are on the horizon that can help bend the curve on both the incidence and the cost of the disease and help patients better manage their disease, how is this commission going to have a role in expediting patient access to these innovations?

Dr. Leffert. So you told us about a very big problem. And we talked about that already. I think the issue for us in terms of getting the treatments to the patients is really one, to some extent, of making sure that the cost is available, that we have treatments that are cost-effective and not so expensive that patients can afford them, but in addition, the commission will allow us to utilize the resources of multiple different agencies working together to be able to first move these new technologies forward -- the artificial pancreas being one of them, particularly in type 1 diabetes -- and then also help us with prioritization of the ability to educate the physician workforce.

We have 5,000 endocrinologists in the United States. That is not nearly enough to take care of diabetes. We have to educate and maintain that workforce at the primary care level and with all clinicians who are taking care of people with diabetes. So it is a tremendous

opportunity here to utilize this commission to then focus our efforts at the level of the clinical physician and associated healthcare providers to be able to give these patients the best care.

Mrs. Brooks. And is that being done? Because I am a huge believer in public/private partnerships, especially when it comes to commissions and government commission work, and so is involving the private sector clinicians on the commission the manner in which you are going to educate the agencies?

Dr. Leffert. To some extent I think that is exactly the reason for our bill. This bill started within our organization in being interested in trying to make sure that the flow of dollars coming from the Federal Government was adequately being utilized to take care of patients. Our organization, the American Association of Clinical Endocrinologists, are the physicians on the ground who take care of patients on a daily basis. We have the ability to see, though, not all of the patients that have diabetes. We focus, to a large extent, our efforts on complicated patients. And we want to be able to translate our knowledge and information throughout the system. And so that allows us to give primary care physicians the information and education, and we need the Federal Government to be able to push that through to the whole sector of physicians who take care of patients.

Mrs. Brooks. Thank you.

Dr. Morrison, in your opening statement you talked about your concern, and there has been a lot of attention on opioids, and we just passed and had signed into law a very significant piece of opioid

legislation. My involvement with that involved, actually, a task force focused on the prescribing practices of physicians. And can you please speak to the impact of that legislation or what your concern is? And we did add pain specialists to our task force because we want to ensure that patients who need opioids get them. But can you talk about that balance when we have an opioid epidemic happening in the country?

Dr. Morrison. It is a challenge. And I recognize in many respects and I am envious I am not in your position about how to address it. But let me address a couple things.

First of all, there are really two populations of patients to think about when we talk about pain. First, there are the people who live with chronic pain and pain is their only symptom. The much larger population, and the one that we are focusing on here, is the patient population with serious illness where pain is just one of a number of distressing symptoms, so, for most people, pain, breathlessness, fatigue, anxiety. And it is a constellation. And yet the prescribing practices that we need to teach are very similar within both populations. And I often hear about: Well, we are going to carve out people with cancer or people at the end of life, and they are not going to be part of the legislation. The reality is, though, that that is only a small fragment of those with serious illness, that people are going to live for many years with pain, distressing symptoms, and they are not going to be treated by specialists. They are going to be treated by primary care physicians, cancer doctors.

And so what we need to do is we need an aggressive effort that is going to focus on teaching appropriate opioid prescribing. But, as importantly, it still strikes me as almost unimaginable that the drug we have for pain has not changed since the 1600s and that we need major investment in alternatives to a drug that we know has not only significant side effects but significant complications. So we need to teach appropriate opioid prescribing, appropriate recognition of the signs and symptoms of addiction, appropriate training into what are opioid-responsive pain syndromes and what are not, and we really need a critical investment in research to give us an alternative to opioids to treat pain and other symptoms.

Mrs. Brooks. Thank you very much.

I yield back.

Mr. Pitts. The chair thanks the gentlelady and now recognizes the gentleman from New York, Mr. Engel, 5 minutes for questions.

Mr. Engel. Thank you, Mr. Chairman and Mr. Green, for convening this morning hearing. I am so pleased to have an opportunity to discuss H.R. 3119, the Palliative Care and Hospice Education and Training Act, a bill that I introduced with Congressman Tom Reed, my colleague from New York. Every one of us has been touched by serious illness, whether we have been affected personally or stood by a loved one grappling with critical illness. We all know how physically and emotionally trying situations can be for all those involved. Palliative care aims to relieve these stresses.

And thank you, Dr. Morrison, for everything you have been saying.

I am from New York City as well. Palliative care complements efforts to treat or cure illness by focusing on patients' quality of life. Palliative care is appropriate for patients with serious illness, starting at the point of diagnosis through treatment and onward through hospice and the end of life. It involves capable communication with patients and their families to coordinate care, determine preference, and help with medical decisionmaking throughout the care continuum. Despite the benefits of palliative care, many Americans aren't aware of the supports available to them. In addition, there is a shortage of educated providers who can offer quality palliative care.

So my bill, H.R. 3119, aims to remedy these issues. My bill would expand opportunities for training in palliative and hospice care and offer incentives to attract and retain providers. In addition, through existing programs, my bill would create a national campaign to educate patients, families, and health professionals about the benefits of palliative care. And, finally, H.R. 3191 would expand critically needed research on palliative care at the National Institutes of Health.

I want to thank Chairman Upton, Chairman Pitts, Ranking Member Pallone, Ranking Member Green, for considering this important bill. And I would also like to thank the 200 Members, colleagues of House, who have cosponsored it, including several members of this committee. And I hope today's discussion, as it has been doing, will bring us one step closer to enacting this legislation and extraordinarily improving

patients' quality of life.

So let me, Dr. Morrison, thank you again for being here today. During your testimony, you noted that palliative care has the potential to bring about long-term savings for the healthcare system. Would you explain exactly how improved access to palliative care and, specifically, this bill would produce these savings? And have there been studies that actually conclude that there are real savings?

RPTR BAKER

EDTR SECKMAN

[12:00 p.m.]

Dr. Morrison. Before answering your question, Mr. Engel, thank you, on behalf of the patients and families that I take care of. I live just south of your district.

Mr. Engel. Move on up.

Dr. Morrison. Thank you for sponsoring this legislation. The question is, will palliative care provide savings to the healthcare system? And the answer is, yes, it will. When we look at the population that palliative care provides for, it is the 5 percent of Medicare beneficiaries that are accounting for over 50 percent of spending. And what palliative care does is it provides the added layer of support that reduces the misutilization for that population. How does it do that? First of all, it provides a safe environment at home, so the in the setting after crisis in the middle of the night, on a weekend, or any time that is not Monday to Friday, 9 to 5, it provides the added layer of support at home so that somebody doesn't have to go to the emergency department for care. Our modern-day hospitals are designed for the 95 percent of people who don't need palliative care, and it is a mismatch, a tremendous mismatch for somebody with multiple chronic conditions, cognitive impairment, frailty, in our modern hospitals. And what palliative care teams do is they provide that added layer of support and make the hospitals friendly to people with

chronic illness. They address pain and other symptoms. They sit with patients and families and identify: What are their values? What are their goals for care? What are they hoping to accomplish? And then we match treatments to meet those goals, and in doing so, we reduce unnecessary and unwanted healthcare utilization. And conversely to hospice, we do this at the same time as all other appropriate life-prolonging treatments.

The question about cost and cost savings is an important one. We now have studies in general hospitals within the Medicaid population, within the Veterans Administration, all that demonstrate that when palliative care is provided at the same time as other appropriate treatments, costs are dramatically reduced, and importantly, quality of life goes up, and survival is exactly the same, if not longer.

Mr. Engel. I think the point about survival certainly the same, if not longer, how do efforts to better patients' quality of life simultaneously enhance patients' clinical outcomes, you know, the tie-in between the two?

Dr. Morrison. How does palliative care enhance clinical outcomes? We don't know for sure, but we have a very strong hypothesis why. First of all, we know that people living in pain, people who are depressed, people who are anxious, all contribute to increased medical complications. Pain is associated with delirium and confusion. Pain means that you can't get out of bed and walk, so you lose muscle mass. Pain prevents you from eating because you just don't feel hungry. Nausea does the same. So palliative care, by specifically focusing

on distressing symptoms, allows people to get better.

The best example I can give is my 35-year-old who had a very aggressive lymphoma but because of the palliative care she received, she made every single one of her chemotherapy appointments on time because she wasn't too nauseated, too sick, too distressed, and subsequently, she made every single radiotherapy on time and completed her treatment, so the palliative care she provided allowed her to complete her curative treatments.

Mr. Engel. Thank you.

Mr. Chairman, can I please ask unanimous consent to enter into the record statements in support of H.R. 3119 from the Alzheimer's Association, the American Academy of Hospice and Palliative Medicine, the National Hospice and Palliative Care Organization, and the Oncology Nursing Society, as well as a letter of support from the 45 organizations on record in support of the bill?

And I want to thank Dr. Morrison for being the most eloquent speaker on this that I have heard. Thank you.

Mr. Pitts. Without objection, so ordered.

[The information follows:]

******** COMMITTEE INSERT ********

Mr. Engel. Thank you, Mr. Chairman.

Mr. Pitts. The chair thanks the gentleman. That concludes the questions of the members of the committee present. We will have some followup questions, questions in writing. We will provide those to you. We ask that you please respond promptly.

I remind members that they have 10 business days to submit questions for the record, so members should submit their questions by the close of business on Thursday, September 22.

Very interesting, very important, very informative hearing. Thank you very much for your testimony.

And, with that, this hearing stands adjourned.

[Whereupon, at 12:05 p.m., the subcommittee was adjourned.]